Reducing inequalities and promoting inclusion (target 10.2)

Goal 10 aims at reducing inequalities and target 10.2 aims at empowering and promoting the social, economic and political inclusion of all, irrespective of disability status. Community support systems are central to the inclusion of persons with disabilities and thus for achieving target 10.2. These systems provide support to enable persons with disabilities to participate in school, the workplace and in communities on an equal basis with others. The community support needed varies from person to person and may include financial support, family support, personal assistance, community-based networks, provision of assistive technology, transport and housing programmes and supported decision-making.

The Convention on the Rights of Persons with Disabilities requires States to ensure that persons with disabilities have access to a range of support services to facilitate living and inclusion in the community. Community support and inclusion are cross-cutting obligations found in the purpose of the Convention (article 1), the general principles (article 3), the general obligations (article 4), as well as in the context of several substantive provisions, in particular the right to live independently and be included in the community (article 19) as well as the right to an adequate standard of living and social protection (article 28). Providing support to persons with disabilities to exercise their legal capacity is also required (article 12). Similarly, providing comprehensive services and support to children with disabilities and their families to prevent segregation of these children is required (article 23(3)).

The Human Rights Council has adopted a number of resolutions addressing community support and independent living, including in 2015 a resolution on the right of persons with disabilities to live independently and be included in the community on an equal basis with others,[418] which calls on States to provide persons with disabilities with access to a range of support services that are responsive to their individual choices, wishes and needs, including for their deinstitutionalization. The Council has also urged States to provide services and support systems across different issues, such as mental health[419] and violence against women and girls.[420]

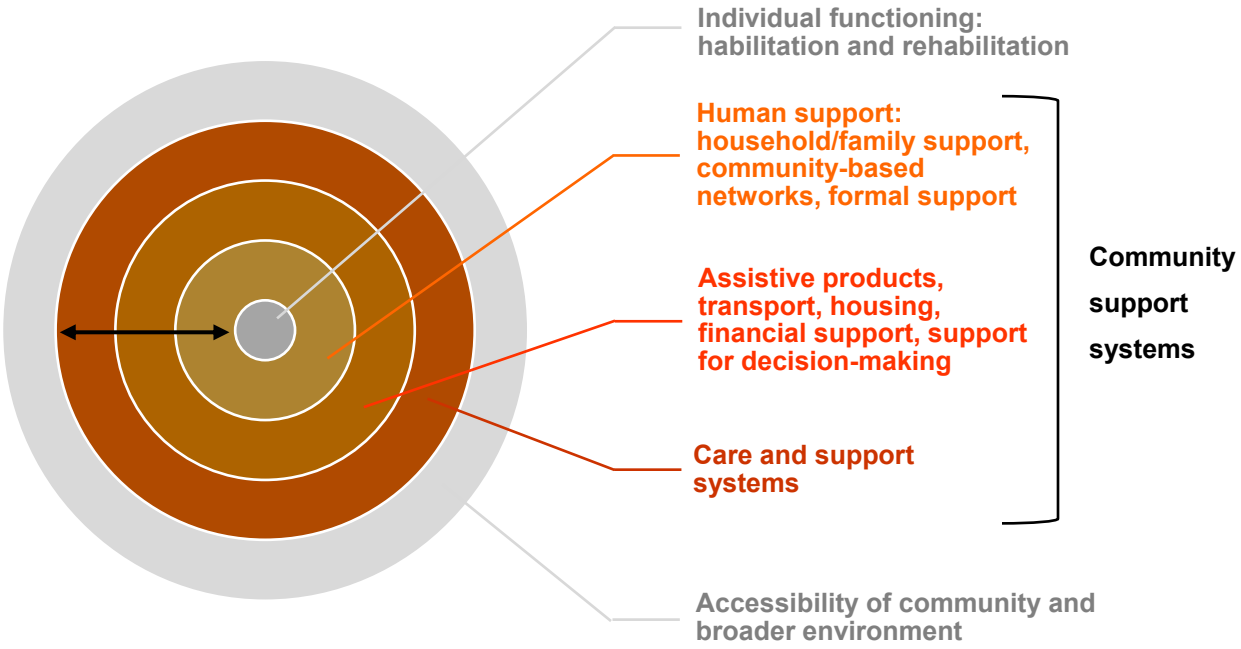
This chapter provides an overview of the availability and access to community support and care for persons with disabilities and their families, with an emphasis on developing countries. It finishes with recommendations on how to address unmet needs for community support for persons with disabilities.

Current situation and progress so far

Community support systems refer to the network of people, services and products that assist persons with disabilities to carry out daily life activities and participate in their communities, including: (i) human support, assistive technologies and inclusive transportation; (ii) financial support for covering extra costs related to the individualized support needed to prevent their exclusion from community life; (iii) housing assistance, both through cash transfers and social housing, that enable them to live in the community; (iv) support to exercise legal capacity, including through supported decision-making; (v) family support

programmes, including social protection schemes to reduce the impact on available household income where services are insufficient; and (vi) care and support systems, including other community-based services needed to prevent institutionalization.

Figure 160. Interdependence among community support systems, improvement of individual functioning and accessibility of the community and broader environment.



These community support systems are essential to overcome exclusion, prevent institutionalization, live independently in the community and support families of persons with disabilities. They enable inclusion by mobilizing communities and coordinating a diversity of schemes and services, connecting and leveraging inclusion efforts made by different sectors. Participation and inclusion are maximized where different types of support are available and operate in synergy to produce an enabling environment for all, including persons with disabilities.

There is an interdependence among (i) community support systems; (ii) improvement of individual functioning through habilitation and rehabilitation; and (iii) accessibility and inclusiveness of the community and broader environment (Figure 160). For example, improving individual functioning through habilitation and rehabilitation and increasing accessibility of the environment through universal design helps reduce the need for human support services. Having access to assistive technologies or human support helps navigate inaccessible environments and information, which are still the norm around the world.

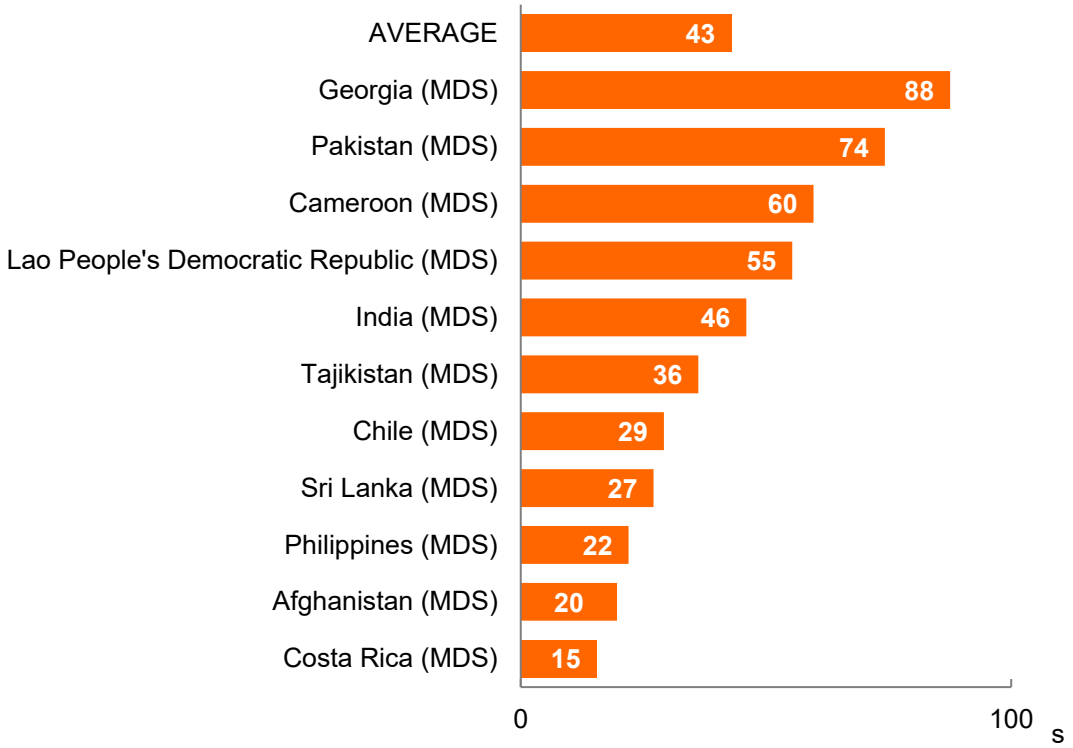
However, even where the environment is accessible, mainstream services are inclusive, and quality

habilitation and rehabilitation are available, individualized support may still be required to ensure the participation of persons with disabilities who face more severe functional limitations. The lack of community support services can negatively impact persons with disabilities and their families in various ways, including by inducing dependency, segregation and putting persons with disabilities at higher risk of violence and abuse.

Persons with disabilities have a range of unmet needs in relation to accessing services, financial and social support and other social resources, finding support for communication and socialization, getting information and, among parents of children with disabilities, receiving support for childcare.[421] While developed countries spend 1 per cent to 5 per cent of their gross domestic product (GDP) on disability benefits and support, developing countries spend only between 0.001 per cent and 1 per cent of their GDP (see the chapter on targets 16.5, 16.6 and 16.7).

In many communities, the support systems for persons with disabilities are insufficient, impeding persons with disabilities from participating on an equal basis with others. Among 11 developing countries, on average, 43 per cent of persons with disabilities indicate that joining community activities is problematic or very problematic, from 15 per cent in Costa Rica to 88 per cent in Georgia (Figure 161).

Figure 161. Percentage of persons with disabilities who indicate that joining community activities is problematic or very problematic, in 11 countries, in 2021 or latest year available.

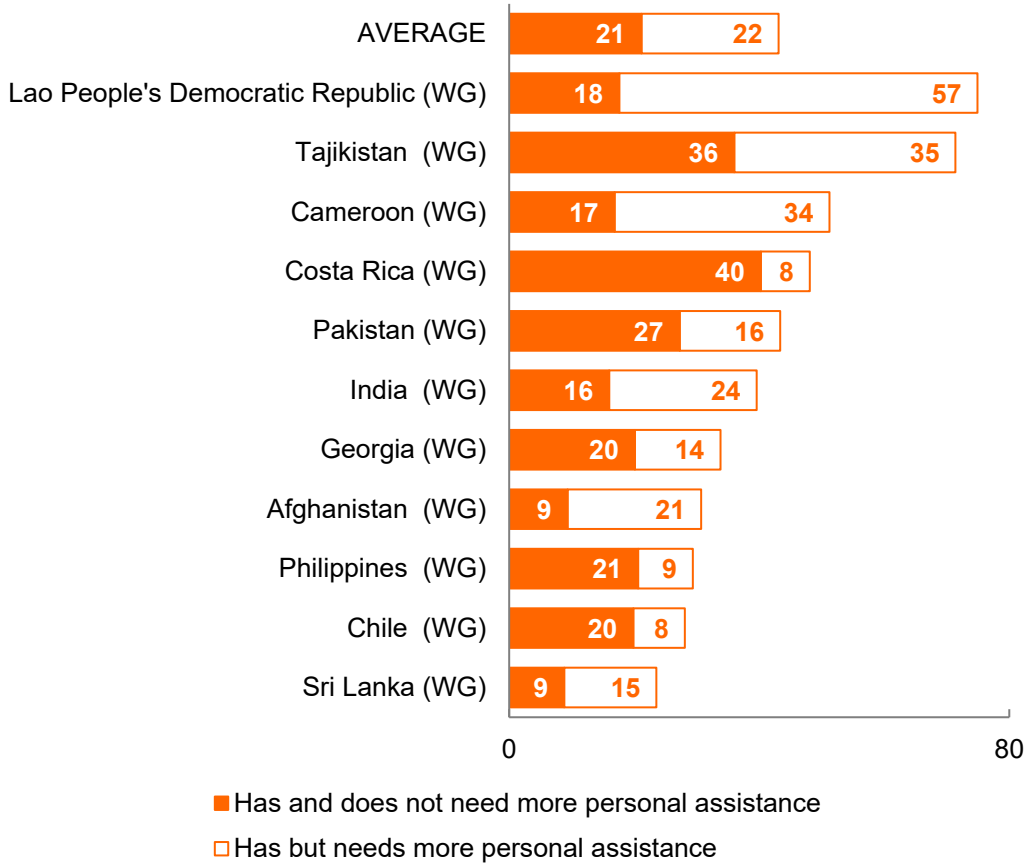


Note: (MDS) identifies data produced using the Model Disability Survey.
Source: WHO (on the basis of data from Model Disability Surveys).

Human support

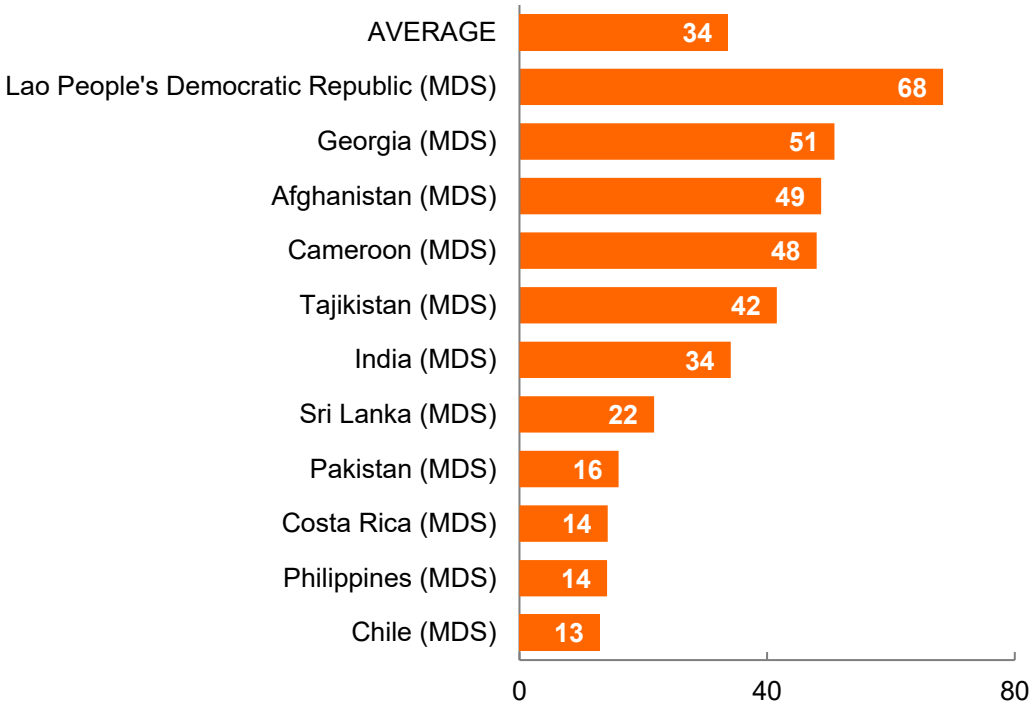
Many persons with disabilities, particularly those with long-term impairments, require human support throughout the life cycle to participate in the community equally and with dignity, autonomy and choice. Human support can involve formal or informal care, personal assistance services, sign language interpretation, guide-interpreters for deafblind people, peer support groups, circles of support, and other support networks and services. This support is required in various life domains, including communication, decision-making, personal mobility, self-care, daily living activities, as well as access to public services, education and work. The level of support required varies depending on the individual's level of functional limitation; the barriers in the home; community, transport, school or work environments; and the individual's desired level of participation.[422]

Figure 162. Percentage of persons with disabilities receiving sufficient and insufficient personal assistance for day-to-day activities at home or outside, in 11 countries, in 2021 or latest year available.



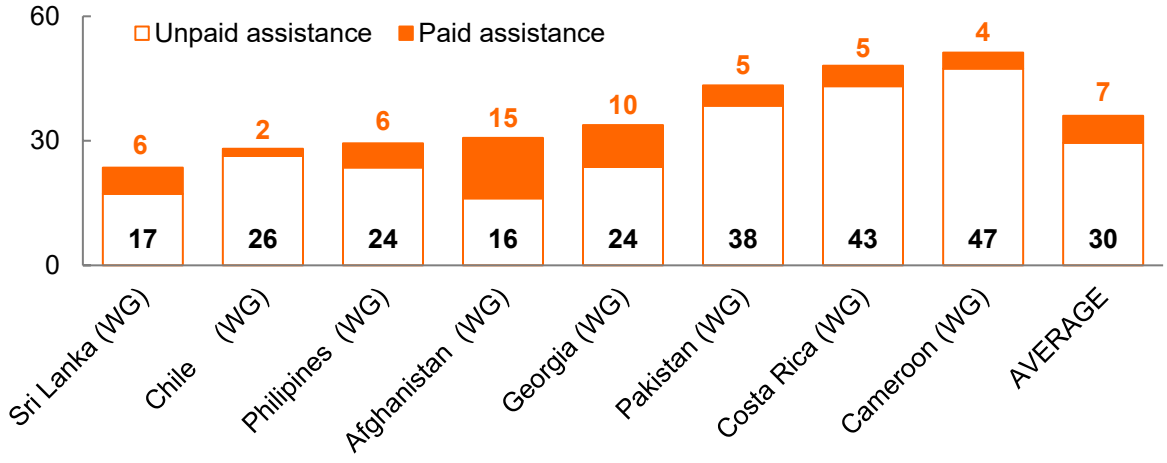
Note: (WG) identifies data produced using the Washington Group short set of questions on functioning.
Source: OHCHR (on the basis of data from MDS).

Figure 163. Percentage of persons with disabilities who need personal assistance for day-to-day activities at home or outside, among persons with disabilities who do not have any personal assistance, in 11 countries, in 2021 or latest year available.



Note: (MDS) identifies data produced using the Model Disability Survey.
Source: WHO (on the basis of data from the MDS).

Figure 164. Percentage of persons with disabilities receiving unpaid and paid personal assistance, in 8 countries, in 2021 or latest year available.



Note: (WG) identifies data produced using the Washington Group short set of questions on functioning.
Source: OHCHR (on the basis of data from Model Disability Surveys).

Among 11 countries, on average, 43 per cent of persons with disabilities receive personal assistance for day-to-day activities (Figure 162). Despite this considerable level of support for day-to-day activities, unmet demand for human support remains substantial, with 22 per cent of persons with disabilities indicating that they need more support in addition to the support they are receiving. Moreover, among persons with disabilities who do not have personal assistance, 34 per cent would need this assistance, indicating an important gap that restricts their full participation and puts them at risk of exclusion (Figure 163).

Most of the personal support persons with disabilities receive is unpaid, mainly provided by family members (Figure 164). Paid personal assistance tends to be costly[423] and many persons with disabilities who need it cannot afford it, leading to their disempowerment and leaving them at risk of isolation, poverty, violence, abuse and institutionalization.

Historically, developed countries did not invest adequately in community support systems and relied heavily on segregated settings to provide human support, a practice that continues today. Recently, some countries have shifted towards personalized schemes for the provision of human support.[424] Developing countries tend to invest little to none in human support for persons with disabilities, as families are expected to provide such support without government assistance. Nevertheless, there are examples that show that investment in human support is also possible in resource-constrained settings when government initiatives are combined with community resources. For example, in Thailand, publicly funded personal assistance and sign language interpretation are provided to persons with disabilities through government disability centres and representative organizations of persons with disabilities.[425] Other developing countries that have developed personal assistance schemes include Argentina,[426] Bulgaria,[427] Costa Rica,[428] Iraq,[429] South Africa[430] and Tunisia,[431] albeit with various degrees of coverage, scope and success.

Family support programmes

Families are generally the main support network. In fact, in most countries, they are the main and often sole source of support for persons with disabilities of all ages. Support from family members has advantages: family members are often well-placed to understand the support needs and preferences of their relatives with disabilities and, because they have close ties with the community, their local knowledge and existing connections can benefit persons with disabilities. For children with disabilities, families play a critical role in child development and serve as role models for children to learn new skills and engage in the community.

While some persons with disabilities may prefer to receive support from family members, to complement or as an alternative to formal services, having families as the only source of support has limitations. The support that families can provide is often insufficient as it may be limited in terms of time, financial resources and knowledge. Furthermore, persons with disabilities may lack choice and control about the

support they receive. On the part of family caregivers, they may have to reduce or stop their own work or education to support their relatives with disabilities. Where they are the primary providers of care and support and do not receive appropriate support, they may risk burnout, and this could lead to neglect, abuse and institutionalization of persons with disabilities.

Several countries have invested in support programmes to assist families of persons with disabilities in their support role. Developing countries with disability-inclusive family support programmes include Brazil,[432] Colombia,[433] Ghana[434] and Rwanda.[435]

Assistive technology

Access to assistive technology is a pre-condition for inclusion and participation in all domains, including within education, political and civic life, employment and social and family life. Despite the great demand for assistive technology, a large number of persons with disabilities continue to face barriers to accessing such technology. Access to assistive technology varies from 11 per cent in countries with a low human development index to 88 per cent in countries with a very high human development index (see the chapter on target 17.8). The most commonly reported barrier is affordability, faced by 31 per cent of persons with disabilities (see the chapter on target 17.8). Social protection can thus assist with providing assistive technology, through health insurance, subsidies, cash transfers or direct provision.

Transport programmes

To access health, education and employment, persons with disabilities need accessible, affordable and reliable transportation systems. However, many public transport systems are either completely inaccessible or difficult to access. In developing countries, 43 per cent of persons with disabilities consider that transportation is not accessible to them (see the chapter on Goal 11). Barriers include poor vehicle design, bad platform accessibility of stations, lack of elevators and inaccessible signage and announcements. In rural communities, public transportation is generally in short supply due to a lack of funding and poor infrastructure.

Faced with this situation, various countries have adopted legal requirements on accessibility for persons with disabilities in public transportation and developed partnerships with representative organizations of persons with disabilities to implement accessibility features in various modes of transport (see the chapter on Goal 11). Some cities are also investing in paratransit solutions that provide individualized door-to-door transport. For example, in Cape Town, South Africa, a programme known as Dial-A-Ride provides accessible transportation to persons with physical disabilities who face barriers in accessing general public transport.[436] Although persons with disabilities have reported some problems with paratransit, such as the lack of training of bus drivers, restrictive eligibility criteria and slow service, these programmes remain necessary to ensure the full inclusion of persons with disabilities in their communities. In developing countries with underdeveloped public transportation, door-to-door transport may be the only

viable mobility option. In Phnom Penh, Cambodia, and in Karachi, Pakistan, low-cost wheelchair accessible *tuks* and *autorickshaws* have been developed to provide transport to persons with physical disabilities.[437]

To compensate for the extra cost of transportation that persons with disabilities may incur, either due to the lack of accessible transportation or the need to have a companion, several countries have also implemented transportation subsidies. For example, the city of Bogota, Colombia, provides transport subsidies to persons with disabilities through smartcards.[438]

Housing programmes

Housing programmes are essential for the inclusion of persons with disabilities in their communities. The lack of adequate housing aggravates the marginalization and dependency of persons with disabilities. The concept of housing involves more than physical shelter: it includes the notion of adequacy, which encompasses accessibility, affordability, independence, security, legal tenure, appropriate location, habitability, cultural adequacy and availability of services, materials, facilities and infrastructure.[439]

Persons with disabilities encounter numerous barriers to accessing adequate housing, including stigma and discrimination, low income, and laws and policies that legitimize institutionalization. As a result, they are disproportionately likely to experience homelessness or to be institutionalised.[440] Those with the opportunity to live in the community, experience barriers such as inappropriate and inaccessible housing design, lack of participation in housing programme design and inadequate housing support. In developing countries, 33 per cent of persons with disabilities consider their dwelling not accessible to them (see the chapter on Goal 11).

Some countries have programmes and services that help persons with disabilities to find and afford a place to live, or to modify an existing home to make it accessible, such as housing counselling, public housing programmes, rental assistance, vouchers programmes and supported housing.[441] At the same time, in response to the call for deinstitutionalization, there has been an increase in group homes in a number of countries,[442] including in developing countries,[443] which undermines community inclusion efforts. In such settings, large power imbalances between staff members and residents remain, choice and control are limited, and residents are more likely to be exposed to violence, abuse and neglect.[444]

Financial support

Persons with disabilities incur substantial extra costs associated with disability, such as costs related to healthcare, accessible transportation, personal assistance, modified residences and assistive technology, making inclusive social protection systems a prerequisite for community inclusion. These extra costs amount to about 43 per cent of household income in developed countries and 23 per cent of household income in developing countries (see the chapter on Goal 1). Financial support enables income security,

the ability to pay for support services, an increase in households' investment in children with disabilities, and an improvement in households' coping strategies. Many governments have started investing in social protection programmes for persons with disabilities, with 99 per cent of countries worldwide having some kind of disability benefits (see the chapter on Goal 1). Non-contributory cash transfers (such as disability benefits, social welfare pensions, conditional cash transfers) have been used to benefit both children, working-age adults and older persons with disabilities because they are not limited to only persons who have worked in the formal sector and contributed to social protection,[445] but these schemes are far from the norm with 48 per cent of countries not having any non-contributory scheme (see the chapter on Goal 1). Some countries have further utilized "cash-plus" programmes, providing cash transfers along with additional components such as information and additional benefits and support.[446] Despite these initiatives, the percentage of persons with disabilities who receive disability benefits remains low (these benefits only reach 34 per cent of persons with severe disabilities) and, in most cases, the amount allocated is insufficient to cover extra costs related to disabilities (see the chapter on Goal 1).

Support for decision-making

Some persons with disabilities may need assistance making decisions about living arrangements, healthcare, relationships and financial or other matters. Supported decision-making is an important example of such support. The term refers to the regimes or arrangements for assisting an individual to make, express and implement a decision. These vary in formality, intensity and scope, and may include support networks, support agreements, peer support, support for self-advocacy, independent ombudspersons and advance directives. The supporters are selected by the person with disabilities themselves and they can be inter-alia family members, co-workers, friends or past or present providers. Although supported decision-making tends to have a defined structure and process, it is also flexible and can be adapted to meet an individual's situation and needs. Instead of making a decision, the supporters respect the will and preferences of the individual and honour the choices and decisions the individual makes.

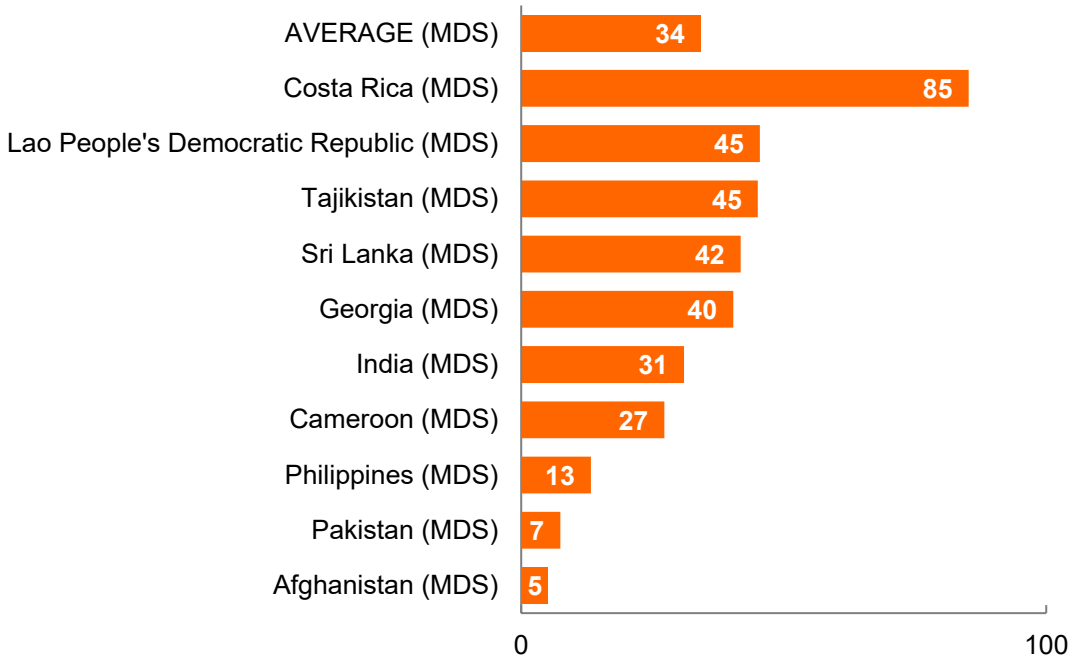
However, this type of support is still seldom available (see also the chapter on target 16.3). Instead, many persons with disabilities face barriers to making their own decisions and very often someone else is designated to make decisions for them. Among 10 countries, on average, only 34 per cent of persons with disabilities completely make decisions about day-to-day life and big decisions (such as where to live, who to live with and how to spend money), from 5 per cent in Afghanistan to 85 per cent in Costa Rica (Figure 165).

Since the adoption of the CRPD, several countries have taken measures towards supported decision-making, with varying levels of compliance with this arrangement (see the chapter on target 16.3). For instance, Austria, Colombia, Costa Rica, Peru and Spain have enacted legislation abolishing guardianships alongside the recognition of supported decision-making. Other countries, such as

Argentina, Australia, Brazil, Bulgaria, Canada, Czechia, Hungary, India, Ireland, Israel, Kenya, Latvia, Sweden, the United Kingdom, the United Republic of Tanzania and the United States of America, have introduced aspects of supported decision-making while retaining partial guardianship and other forms of substituted decision-making.

A concern that arises from these reforms is that the recognition of supported decision-making has not been accompanied by the development of services. Most experiences of provision of support for the exercise of legal capacity are on a small scale and come from representative organizations of persons with disabilities and non-governmental organizations; services developed or funded by the state are scarce.[447] One such example is the Supported Decision-Making New York programme,[448] recently expanded with public funding, which provides facilitation to ensure that people are assisted to implement supported decision-making agreements. In Catalonia, Spain, Support-Girona – an organization originally created to assume the traditional role of a guardian – provides support for decision-making to individuals dealing with complex situations and at risk of abandonment or institutionalization.[449] The government provides a personalized budget for each user.

Figure 165. Percentage of persons with disabilities who completely make decisions about day-to-day life and big decisions (e.g., where to live, who to live with and how to spend money), in 10 countries, in 2021 or latest year available.

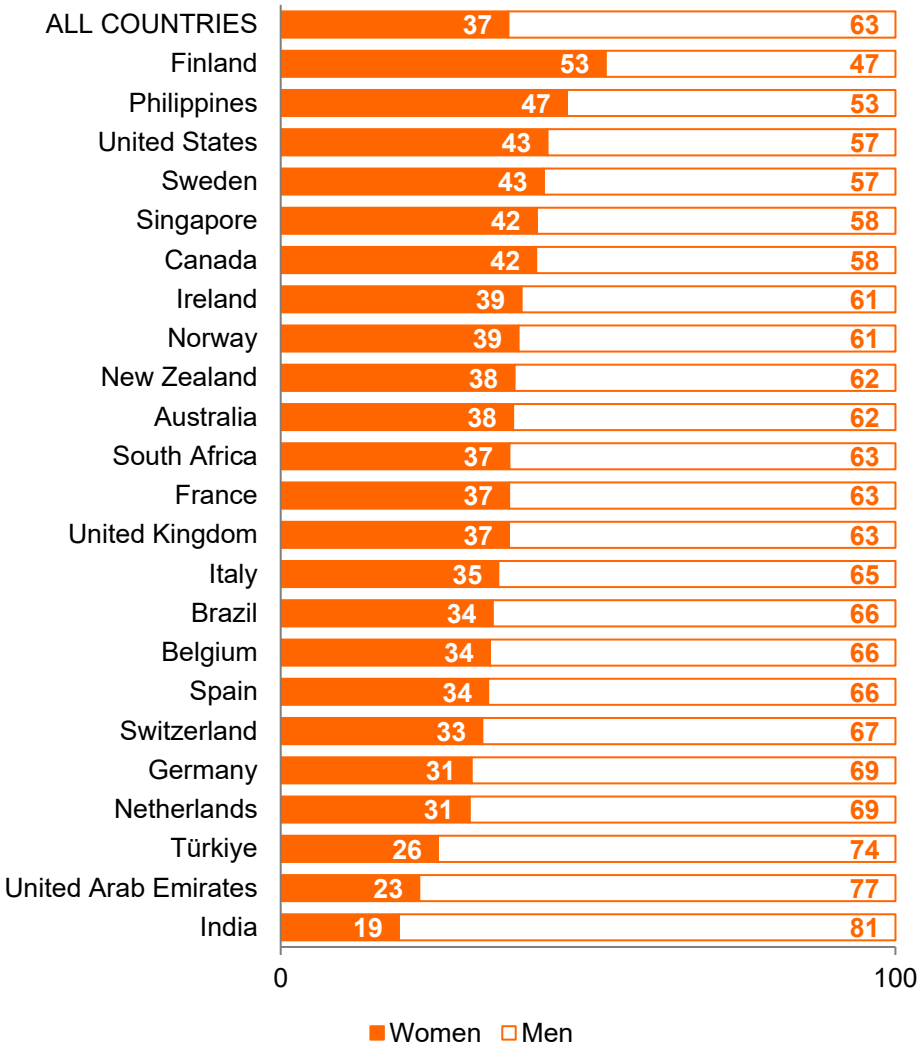


Note: (MDS) identifies data produced using the Model Disability Survey.
Source: WHO (on the basis of data from the MDS).

Care and support systems

The COVID-19 pandemic has increased the visibility of the care economy agenda resulting in the mobilization of unprecedented political support to develop and strengthen care and support systems, ensuring access to care and support for people who need it, and guaranteeing the rights of those who provide it. There is also greater awareness of the impact of demographic changes. Various factors, such as population ageing, shrinking families and women's increased participation in the labour force, have resulted in more people who need care and fewer people available to provide care.[450]

Figure 166. Percentage of directors and managers in services for persons with disabilities who are women, in 23 countries, in 2022.



Source: Country estimates calculated using data from LinkedIn.com.

Many persons with disabilities cannot afford formal care and support, that is, paid care provided by professional services. Moreover, the leadership of formal care and support systems tends to be occupied by men, which may pose barriers to integrate the perspectives of women in formal care and support systems for persons with disabilities. An analysis of social media data in 2022 indicated that the percentage of women directors or managers in services for persons with disabilities was 37 per cent compared to 63 per cent of directors or managers who are men (Figure 166). In some countries the percentage of women directors or managers in these services is as low as 19 per cent while in other countries similar percentages of women and men work as directors or managers of services for persons with disabilities.

For informal care and support (unpaid care and support provided by family or others such as neighbours or friends), the opposite tends to happen with more women than men assuming these roles. The care economy agenda has placed particular emphasis on this issue, focusing on enabling women's full participation in the economy and advancing gender equality, as the distribution of informal care and domestic work between men and women remains unequal. Girls and women are disproportionately tasked with informal care and support roles, putting them at higher risk of unpaid work.[451] Currently, the conversation on the care economy is focused on more time to care (such as work leave), compensation for care (such as cash-for-care), and respite from and replacement of care (such as respite services).

However, what is at stake for persons with disabilities remains relatively underexplored. Even though they are considered as one of the target populations, alongside children and older persons, they are not actively engaged in policy discussions and reform. Thus, their perspectives and lived experiences have yet to be reflected in the care agenda. Historically, representative organizations of persons with disabilities have been critical of the idea of "care" and "dependency" as persons with disabilities have been treated as "burdens" and "objects of care" rather than as rights holders bearing choice and control over support networks and services. In many countries, the negative legacy of care systems and services persists, impeding persons with disabilities from exercising their rights to live independently and be agents in society. This legacy also prevents the positive economic returns and social benefits for the wider community created by inclusive care and support systems. As such, representative organizations of persons with disabilities have been advocating for a move away from traditional "care" models and toward a support paradigm which recognizes support as an individual right with an obligation on countries to enable personal choice and control across all areas of life.

Deinstitutionalization

A large number of persons with disabilities across the world are institutionalized in mental health or social care facilities in contravention of the CRPD. In the European Union, it is estimated that there are still around 1.5 million persons living in institutions.[452] In the global South, official statistics are scarce, partly due to the proliferation of informal and private institutions.[453] Data from nine developing countries indicate

that, on average, 8 per cent of persons with disabilities have lived in an institution or special home for persons with disabilities at some point in their lives.[32]

Rates of institutionalization of children with disabilities remain high in many countries, including increasingly in many developing countries. In 2015, global estimates of children living in institutions were as high as 5 million,[454] but the true figure may be higher given the gaps in global statistics and indications that there are many unregistered children's homes.[455] Developed countries had the highest average prevalence of institutionalization, whereas developing countries had the lowest average prevalence. South Asia had the largest estimated number of children living in institutions (1.13 million), followed by Europe and Central Asia (1.01 million), East Asia and the Pacific (0.78 million), sub-Saharan Africa (0.65 million), Middle East and North Africa (0.30 million), Latin America and the Caribbean (0.23 million) and North America (0.09 million). While these numbers include children with and without disabilities, children without disabilities living in institutions are especially at risk of developing disabilities. Children in institutions tend to face neglect as well as chronic deficit of physical and emotional attention and affection, which are risk factors for developing disability. Data from Central Asia and Eastern Europe indicate that one third of children living in institutions are children with disabilities.[456]

Institutions keep persons with disabilities excluded from society and deprived of their liberty. Many institutions prevent persons with disabilities from accessing education and political participation and from making decisions about their own lives. Many institutions subject persons with disabilities to isolating, sub-standard and unhygienic living conditions and to torture and inhuman and degrading treatment, including forced sterilization and other coercive practices. Deinstitutionalization is not just crucial to ensure community inclusion, it is a human rights imperative.

Deinstitutionalization is more complex than simply shutting down institutions and changing place or type of residence. For deinstitutionalization to work, a range of community-based support networks and services must be in place to enable persons with disabilities to exercise choice and control over their lives. Moreover, additional financial resources are required to afford the double running costs of investing in community support networks and services while keeping some institutions operating during the transition period.

Several countries with a legacy of institutionalization are transitioning towards community-based care. For example, Croatia, Moldova and Romania have adopted policies and programmes to end institutionalization and expand community support systems.[457] However, a significant increase in financial resources is required to fully achieve this objective. To address this financial challenge, Italy adopted a law on support measures for persons with disabilities, which includes a dedicated annual fund to foster deinstitutionalization and the development of community-based services.[458] At the same time, some developing countries with historically low levels of investment in care systems, have begun to consider developing institutional care for working age adults with disabilities as well as older persons.[459] This trend shows the need to systematize past lessons from institutionalization and reinforce a robust economic and

human rights case against institutionalization.

Towards comprehensive community support systems

A number of countries have taken steps towards implementing comprehensive community support systems, which combine different types of interventions. For example, in Australia, the National Disability Insurance Scheme facilitates access to information, individualized support and services for persons with disabilities, their families and carers.[460] The types of supports that National Disability Insurance Scheme may fund include support for daily activities, consumables, transport, workplace help, therapeutic supports, lifelong learning, help with household tasks, assistive technologies and home or vehicle modifications. Individuals have the option to self-manage their funding, which gives them flexibility and choice.

An example of a comprehensive community-based programme for persons with psychosocial disabilities run by a non-governmental organization is the Seher Inclusion Programme in Pune, India.[461] This programme involves the provision of a range of services provided by informal supporters as well as formal services. With the full participation and involvement of the person, holistic assessments of the individual's psychosocial needs (including development needs, barriers to full participation and to the realization of human rights) and other needs (such as social, economic, familial, support and nutritional) are conducted to inform individualized intervention plans. The programme uses a variety of support interventions, including peer support, group support, family support, crisis support and circles of care in the community. Other countries, particularly in Latin America, have focused on the equally important goal of developing a comprehensive care agenda that is inclusive of persons with disabilities, paying particular attention to their right to live independently in the community.[462]

In situations of humanitarian crisis, substantial gaps in access to support networks and services, including cash transfers and human support, are usually exacerbated. In response, a number of support initiatives are being developed in developing countries. In Bangladesh, for example, non-governmental organizations have been working together to promote disability-inclusive disaster risk reduction in flood-prone areas.[463] The project entails interventions at the household and the community levels. It provides support to persons with disabilities to access livelihood opportunities, register for government social protection, access counselling for household preparedness, and establish self-help groups and community-run disaster management committees.

In the 2022 Global Disability Summit, a meeting convened by countries and civil society, a number of international organizations and governments made commitments to take action towards community inclusion. The commitments were aimed at the development, investment and research on assistive technology; and at providing community-based support services as well as social protection schemes to cover extra costs related to disabilities.[464]

Impact of the COVID-19 pandemic

The COVID-19 crisis has highlighted the need for robust support systems for community inclusion. Persons with disabilities, especially those living in institutions, were exposed to infection and death at a disproportionate rate. While persons with disabilities comprise 15 per cent of the world population, they constituted half of the COVID-19 deaths (see the chapter on Goal 3).[465] Moreover, abandonment, isolation and segregation, already present in institutions, worsened during the pandemic. Numerous challenges were documented, including understaffing, inadequately trained staff and staff transfer between institutions, resulting in a lack of day-to-day support that led to catastrophic results. Emergency measures implemented by governments to curb the spread of the pandemic, including confinement of residents and banning visitors, left persons with disabilities completely cut off from the rest of society thereby heightening their isolation and, in the absence of monitoring mechanisms, exacerbating human rights abuses and putting persons with disabilities at higher risk of violence.

The pandemic also took a heavy toll on persons with disabilities living in the community as many persons with disabilities and their families experienced a breakdown of community support networks and services.[466] Personal assistance, home support, informal care, respite services, assistive technologies and other necessary supports to live independently in the community were unavailable or under-resourced. In 2020, 32 per cent of persons with disabilities indicated that the pandemic had reduced their access to personal assistance, repair services for assistive technology or accessibility services like sign language interpretation (see the chapter on Goal 10). In 2021, only 37 per cent of persons with disabilities could use human support like personal assistance and family support compared to 92 per cent before the COVID-19 pandemic; only 49 per cent could use mobility assistive products compared to 86 per cent before the pandemic; and only 4 per cent could use hearing assistive technology compared to 19 per cent before the pandemic (see the chapter on Goal 10). These lack of community services impacted daily activities such as personal care and shopping. For example, in the United Kingdom, during the pandemic, 50 per cent of persons with disabilities stopped receiving health or personal care visits to their homes[467] and 41 per cent of persons with disabilities stopped receiving assistance with shopping (see the chapter on Goal 11). In addition, the closure of schools and workplaces overwhelmed family responsibilities related to informal care and support, particularly for women and girls, thereby deepening gender inequality.

Summary of findings and the way forward

Overall, 43 per cent of persons with disabilities indicate that joining community activities is problematic. A range of community networks and services are beginning to develop in various countries to support the inclusion of persons with disabilities in the community but gaps in these services remain: 22 per cent indicate that they need more personal assistance than they receive; 44 per cent of persons with disabilities who do not have any personal assistance need this assistance; and only 11 per cent of

persons with disabilities in countries with a low human development index have access to assistive technology. Persons with disabilities who need support to make their own decisions seldom receive this support and often someone else is designated to make decisions for them. Only 34 per cent of persons with disabilities indicate that they completely make decisions about day-to-day life, where and with whom to live and how to spend money.

This lack of community support systems sometimes pushes persons with disabilities to be placed in institutions, in contravention to the CRPD. Existing data point to 8 per cent of persons with disabilities having lived in an institution at some point in their lives and that a third of children in institutions are children with disabilities.

The COVID-19 pandemic caused a breakdown of community support networks and services. In 2020, early in the pandemic, 32 per cent of persons with disabilities indicated that the pandemic had reduced their access to personal assistance, repair services for assistive technology and accessibility service like sign language interpretation. This trend continued in 2021, as shown in the percentage of persons with disabilities with access to human support (92 per cent pre-pandemic, 37 per cent post-pandemic), with access to mobility assistive technology (86 per cent pre-pandemic, 49 per cent post-pandemic) and with access to hearing assistive technology (19 per cent pre-pandemic, 4 per cent post-pandemic).

To build back better after the COVID-19 pandemic and leave no one behind, governments need to invest in the development of comprehensive community support systems to enable community inclusion of persons with disabilities. This will require a focus on the provision of individualized support at the community level. There are several actions that countries, international organizations, civil society and other relevant stakeholders must begin to take to implement comprehensive care and support systems for persons with disabilities, including:

1. Adopt legislation and cross-sectoral policies to facilitate access to comprehensive care and support systems for persons with disabilities. National initiatives should be underpinned on gender equality and a rights-based approach to disability and be formulated with the active participation of representative organizations of persons with disabilities. Strengthen policies toward the recognition, reduction and redistribution of care and support work, and invest in accessible and inclusive care and support systems. Develop comprehensive policies that promote cross-sectoral coordination.

2. Invest in developing or scaling up community support and care systems, services and networks. Prioritize person-centred and gender-sensitive approaches that foster choice and autonomy for the diversity of persons with disabilities across the life cycle. Support the innovative and community-based strategies developed by representative organizations of persons with disabilities. Develop investment and financing mechanisms to make community support systems sustainable in the long term. Create and expand formal services and promote partnerships and community mobilization. Train and certify carers, supporters and service providers. Regulate services and working conditions for carers and other service providers. Identify good practices and replicate and scale them up.

3. Invest in support programmes to assist families of persons with disabilities. Governments must invest in this support to allow families to better fulfil their support role and mitigate some of the hardships they experience. This support can include information and counselling services, case management, peer support, respite services, mental health and psychosocial support, and financial support to compensate for the impact on household income.

4. Develop and invest in comprehensive disability-inclusive social protection systems. Adopt legislation, policies and programmes providing for comprehensive social protection tailored to meet the individual needs of persons with disabilities, reduce their vulnerability and to cover direct and indirect extra costs related to disabilities. Involve representative organizations of persons with disabilities in developing these systems.

5. Strengthen governance and build capacity to support community inclusion. Invest in rights-based, accessible and disability-inclusive needs assessment, information management systems, and outreach mechanisms to facilitate planning and service delivery. Prioritize investments in individualized housing support for persons with disabilities in all countries, including in developing countries.

6. Replace segregated institutions with community-based support. Invest in deinstitutionalization programmes that entail shutting down all forms of institutions and developing and strengthening community support services and networks.

7. Invest in accessible and inclusive infrastructure, transport and services. Adopt universal design principles and ensure that laws, policies and programmes providing for accessible infrastructure, transport and information are developed. Institute training and education of human resources of services providers in all sectors to raise their understanding of disability inclusion in service delivery.

8. Reshape the care agenda to be inclusive of persons with disabilities. Apply the human rights model of disability and abandon care proposals that reproduce negative paradigms, such as the creation of new institutions or the provision of financing support only to caregivers instead of directly to persons with disabilities. Clearly articulate the demands for independence and community inclusion of persons with disabilities in the care agenda. Invest in care and support systems that address the needs of persons with disabilities throughout their life cycle: childhood, adolescence, working age and old age. Remove barriers to accessing age-based benefits, while creating a smooth uninterrupted transition in receiving benefits from one age group to another. Actively engage persons with disabilities and their representative organizations in policy discussions and reform of the care agenda.

9. Improve research and data collection on community support. Invest in knowledge, research and innovation on providing community-based support in different contexts. Collect and disseminate data on unmet need for support services; support provision; and persons with disabilities still living in institutions.